

WHAT ABOUT DEAFNESS?

In some medical cases, such as those involving Huntington's, it might seem obvious that we should do whatever we can to treat and cure. However, in other cases, it's not as obvious what we should do, since the traits in questions are not obviously *undesirable* to those affected. One such case is *deafness*. Some people, clearly, consider deafness a burden, particularly those who weren't born deaf. Others take it to provide a ticket to the rich culture of the deaf community.

However, before figuring out whether deafness is *undesirable*, we have to get clearer on what deafness *is*. Here are some facts:

- In the population at large, most hearing loss is the result of *damage to the hair cells which line the cochlea*. Hair cells die from aging, infection or noise damage.
- However, in children, the most common causes of hearing loss are *genetic* causes.
- More than that, most cases of inherited deafness is *recessive*, which implies that most parents of born-deaf children will themselves be hearing.

The latter implies that *one* undesirable thing with deafness might be that most deaf children are different from their parents in an important way. Still, children might be different from their parents in *many* ways without thereby living a worse life. So why should this particular difference be avoided?

The Functional Aspect of Deafness

Deafness is associated with the lack of proper functioning of the auditory faculties. This has implications for the extent to which someone will be able to navigate safely, experience music, etc.

A hearing parent about her deaf child: "Her deafness [...] is a loss; a risk to safety as she walks along a busy street, a barricade to the world of music."

The Social Aspect of Deafness

At the same time, there is more to deafness than its medical aspect. As the case of Martha's Vineyard shows, the extent to which being deaf will be problematic depends, at least in part, on whether society accommodates.

Failing to acknowledge this will leave "the conditions that create social disadvantage or handicap [...] largely unchallenged."

The interplay between these two aspects can be illustrated by the case of *cochlear implants*. At the moment, the technology cannot eliminate deafness. Those critical of it argue that cochlear implants will not make a child deaf from birth into a hearing child who will acquire oral language as she grows up. Instead, she will be an outsider in the hearing world and, if oral language replaces sign language, an outsider in the deaf world too.

A THREAT AGAINST THE DEAF COMMUNITY?

More than this, however, those critical of cochlear implants as well as other ways of trying to minimize the prevalence of deafness in society are also concerned that it amounts to saying—if not explicitly then implicitly—that we don't like deaf people.

Whether or not this is true would seem to depend on two things:

- (a) What kind of *decisions* are we likely to make based on genetic knowledge?
 - *Preparation*. Some parents might feel that they want to know whether or not their child will be deaf for the purpose of preparing themselves for the task, rather than terminating the pregnancy.
 - *Abortion*. Some parents might want to know for the purpose of aborting any deaf children.
 - *Treatment*. Currently, the only kind of gene therapy available is one that delivers copies of the relevant genes to the cells in the relevant part of the body. However, no patient has been treated by this form of therapy. One form of treatment not yet used in humans is *germline therapy*, where genes are altered in the embryo/pre-embryo. Using the latter on humans is controversial since any change would be inherited by the next generation.

(b) *Who* will make the decision?

Here, we can imagine three approaches one might take:

Child-Centered Approach

One approach to take is that we should make decisions based on the interest of the child. Here we can imagine two scenarios:

(i) *Parfit Scenario*: If *this* child had not been born deaf, it would not have existed at all. This would seem to be the case in cases where our only tools are screening and *abortion*.

(ii) *Non-Parfit Scenario*: Here, we are talking about treatments pertaining to one (and the same) particular child. It seems at the very least conceivable that the child might be considered *wronged* by being born deaf.

Problem: What is this “wrong” supposed to consist in?

1. It doesn’t seem that deafness needs to imply *unhappiness*; perhaps it might be more miserable to be a hearing child born to deaf parents than a deaf child born to hearing parents.

2. It doesn’t seem that we can spell it out in terms of having violated her ability to make a *choice*. By the time the child will be in a position to make a choice, it will already be too late.

Community-Centered Approach

Another approach focuses on the interest of the deaf community. Consider two worlds:

World A: Some deaf people.

World B: No deaf people.

Even if everyone were to agree that there is a sense in which *B* is a better world than *A*, one question remains: “Given that we’re in *A*, what are the burdens and costs of getting to *B*, and *on whom will they fall?*”

This is the question someone taking a community-centered approach focuses on.

Problem: It doesn’t seem that this provides an argument for *maintaining* disabilities; if anything, it seems to provide an argument for countering *discrimination* and ignorance.

Adult-Centered Approach

A final approach is to focus on the parents, i.e., the ones typically saddled with making the relevant *choices*.

It seems possible that what the parents want for their child need not be what is best for the *child*. (Think, for example, about parents belonging to religious sects.) This, at the very least, seems to be a relevant consideration in non-Parfit scenarios.

Still, this brings us back to what “wrong” parents can do by choosing to have deaf children, or to not treat them for deafness, if that’s possible.

So, are deaf children, for example, less *happy* than hearing children? This remains to be established.

FOR DISCUSSION

The Article: An opinion piece about the British human fertilization and embryology bill, which, among other things, states that any embryo known to have a serious illness or disability “must not be preferred to those that are not known to have such an abnormality.”

A Question: The author seems to assume that any attempt to prevent the implantation of people with a particular medical condition will always be equal to making a claim to the effect that such people are worth less. Do you agree with this assumption? Why or why not?